

Bereavement and Grief

Linda Nakell, Ph.D. and Patty Hennigan, Ph.D.

Normal bereavement:

Varies among cultural groups;

Lasts at least 2 months up to a year or more, depending on relationship to deceased;

May mimic symptoms of major depression: includes sadness, crying unexpectedly, insomnia, poor appetite and weight loss, and preoccupation with deceased loved one. Can also include hearing the voice or feeling the presence of the deceased, particularly among some ethnic groups. May treat with medicine at any time, depending on severity of symptoms and impact on patient's life.

Emotions associated with grief: shock, denial, anger, bargaining, guilt, depression. People move in, out, and through these emotions in their individual ways.

Grief groups and individual counseling are available through Contra Costa Crisis Center at 1-800-837-1818.

Reactions usually beyond "normal" grief:

1. guilt about things other than actions taken or not taken by the survivor at the time of death;
2. thoughts of death other than the survivor feeling that he or she would be better off dead;
3. morbid preoccupation with worthlessness;
4. marked psychomotor retardation;
5. prolonged and marked functional impairment or depression;
6. prolonged social isolation, withdrawal, or alienation;
7. persistence of a variety of physical complaints without organic cause, including headaches, fatigue, dizziness, or multiple injuries;
8. alcohol or drug abuse; persistent requests for sedatives or narcotics;
9. hallucinatory experiences other than thinking that he or she hears the voice of or sees the image of the deceased person.

Tips on Giving Bad News:

1. Arrange a quiet, private place, and sit down with the patient/family;
2. Invite patient to include at least one family member or friend when possible;
3. Provide limited and focused information—no more than three bits of info.;
4. Solicit and answer questions;
5. Acknowledge patient's feelings through active listening;
6. Promise to work with patient over time to provide treatment and/or support;
7. Empathy! It's ok to shed a tear along with the patient!
8. Remember that people won't remember much of what you tell them due to anxiety. Plan to repeat info at next visit after soliciting what patient remembers.

Predictors of positive caregiving relationships	Predictors of burdensome caregiving relationships
Family resources (<i>continued</i>)	
<ul style="list-style-type: none"> • the caregiving family is able to maintain a future perspective and make future plans 	<ul style="list-style-type: none"> • the caregiver and family are steeped in the problems of the present and are unable to make future plans
Community services	
<ul style="list-style-type: none"> • a day care program is available for the patient • psychoeducation and/or a support group is available for the caregiver • good rehabilitation services are available for the patient • day respite care is available for the family • overnight respite care is available for the family • psychological and family therapy services are available for the patient and family • the caregiver has good relations with the medical and support staff 	<ul style="list-style-type: none"> • a day care program is unavailable for the patient • psychoeducation and/or a support group is unavailable for the caregiver • no rehabilitation services are offered • day respite care is not available for the family • overnight respite care is not available for the family • psychological and family therapy services are not available for the patient and family • the caregiver has conflictual relations with the medical and support staff

Looking Death in the Eye

Death, Grieving, and Families

The death of a patient presents the physician with one of the most challenging situations in the practice of primary care medicine. Negotiating the process of dying can also be one of the most rewarding parts of practice as it brings about an emotional intensity for the patient, the family, and other caregivers that can be moving and healing for all who participate. The knowledge of impending death can facilitate resolution of personal and interpersonal conflicts rooted in previous life cycle stages. Of course, that same emotional intensity can also prove traumatic or bring about long-lasting dysfunction for those families who are unable to resolve the challenges raised by the loss of one of their members.

Our society is only beginning to provide institutional support for patients and families facing these changes. On the whole, we are a culture that denies the reality of death (1). In the health care community, death is an event to be prevented, not accepted, and providers often seek emotional distance from the dying patient and the patient's family. Overtly or covertly, the death of a patient is often seen as a failure of the provider's skills. This aspect of our professional socialization makes it difficult for us to facilitate a healthy dying process for our patients or encourage constructive grieving for their families, and for ourselves. In this chapter we will challenge our culture's tendency to deny death by providing a model for constructive interaction between the medical system, the dying patient, and the family. We begin by making practical suggestions about communicating a terminal diagnosis to a patient and family, then turn to treatment planning and making any decisions to limit treatment, notifying a family of a death, counseling around primary care grief issues, and recognizing unresolved grief reactions.

"I believe you may die from this illness"

Communicating the diagnosis of a terminal illness to a patient and family ideally involves clear, direct statements transmitted with a minimum of anxiety. While sometimes a terminal diagnosis is provided by a specialist, the primary care physician is uniquely qualified to communicate this information because of his or her long-standing relationship with the patient and understanding of the family's issues and needs. Several guidelines for clear communication of a terminal illness include:

- Communicate directly to the patient about the diagnosis, the treatment, and the prognosis of the illness. ("We don't believe your disease is curable.")
- Use clear, simple language. Avoid overmedicalizing or intellectualizing the information.
- Be honest and straightforward about the information as you know it, acknowledging areas of medical uncertainty. ("Most people with this illness survive 6-18 months.") Avoid giving an overly optimistic or overly pessimistic prognosis.
- Look the patient in the eye and speak calmly. Repeat the message several times.
- Avoid arguments over the diagnosis, or other diversions from the message itself.
- Set up another appointment to answer questions that will inevitably arise when the initial reaction wears off.
- Repeat this process with the family present. Create a safe atmosphere during the family conference for people to express their feelings honestly and directly if they so desire.
- Allow people their sadness or anger rather than trying to reassure them or brighten their mood. In this situation, depression can signal healthy anticipatory grieving, a process that needs encouragement rather than suppression.
- Allow patients some hope. Be humble about predicting how long a patient may survive.
- Meet regularly with the patient and family to discuss medical care, prognosis, and individuals' emotional reactions, even when the medical care is being managed by a specialist. Encourage children in the family to be involved in at least some of these meetings.

Dying patients force us to face our own mortality and that of those we love. Facing these personal issues can help us be calm and straightforward when communicating a terminal diagnosis to a patient, or accept a family member's anger on hearing about the death of a loved one (2). With difficult or upsetting cases, discussion with a trusted col-

league can be invaluable, both for the medical consultation and for the emotional support (3).

After hearing about a terminal diagnosis, the families of dying patients experience a period of high stress. Holmes and Rahe found the death of a spouse to be the single most stressful life event an individual encounters. Death of some other family member ranked 4th, after divorce and separation (4). Primary care physicians can do much in the way of prevention by spending a relatively brief amount of time attending to family members' reactions and functioning during the terminal illness phase. Fuller and Geis recommend a "health check" for the spouse or other significant family members of a dying patient (5). This appointment allows the physician to address this person's physical and emotional concerns and to raise questions about sensitive areas such as sexuality and finances. Many of these issues may be best discussed with the couple together.

Often the medical care of terminally ill patients is shared among a number of specialists. The primary care physician is well positioned to be a case manager and coordinate the medical care of the patient among the specialists and between the medical system and the family. Communicating regularly with the specialists involved can avoid the fragmentation of medical care that is so common with complex or terminal cases. Without someone coordinating services, families can receive differing or contradictory messages about a terminal illness.

Dr. E had taken care of the Terrillo family for over 20 years. Mr. Terrillo, the patriarch of the family, had always been in relatively good health, though neither Dr. E nor his family had ever been successful in getting him to stop smoking. Recently, Mr. Terrillo was found to have a lung mass on a chest X-ray done during a physical exam. A chest surgeon biopsied the mass, which proved to be malignant. After this diagnosis, Mr. Terrillo began to see an oncologist and the surgeon on a regular basis, rarely seeing Dr. E. Both specialists confirmed a diagnosis of lung cancer, but were vague to the patient and the family about prognosis. While Dr. E thought of Mr. Terrillo often, he was actually relieved during this difficult period to be able to distance from this man who reminded him of a favorite uncle.

When Dr. E received the specialists' reports on Mr. Terrillo, he found the surgeon and oncologist presented very different prognoses for this patient. Soon after reading these reports, Dr. E received a call from one of Mr. Terrillo's adult children pleading with him to make sense out of what the doctors were telling her stepmother about the prognosis. Dr. E suggested that the daughter convene a family conference at his office in the next week, allowing him time to communicate directly with the specialists involved in Mr. Terrillo's care. When he did so, he found that the surgeon's view was that Mr. Terrillo had several months to live, if that long, while the oncologist was not yet ready to label the patient terminal, saying "There's always hope." Dr. E told the specialists of the family's request for more specific information

his own suggestion for a family conference. He invited the specialists to attend. When both declined, he asked them if they had any special message they would like transmitted to the patient or family. Both reiterated the prognosis as they saw it. Dr. E promised to present both points of view to the family.

Mr. and Mrs. Termillo and three of four of Mr. Termillo's adult children attended the family conference. Mrs. Termillo said she was relieved to be meeting with Dr. E, whom she trusted and had known for a long time. Mr. Termillo's daughter who had requested the meeting appeared nervous and quickly got to her point: "We're having trouble with the specialists because they won't tell us what's really going on with our father." Dr. E asked for others' understanding of Mr. Termillo's prognosis. Mrs. Termillo said she understood her husband was going to die but she did not know how soon. The other adult children split on whether they believed there was any hope. One in particular said she was "not going to sit there and just let him die." Mr. Termillo sat through the meeting passively. When asked his own feeling about his prognosis, he said "I don't know."

Dr. E spent the rest of the conference reviewing the reports from both specialists, presenting their differing points of view as well as the available statistics for the particular stage of Mr. Termillo's cancer. As everyone was encouraged to air their feelings, it became more clear that much of the pent-up frustration and anger about Mr. Termillo's illness was being directed at the medical system. At this point, Mr. Termillo asked, "Dr. E, do you think I will die from this?" Dr. E said, "Given the reports from the specialists and the statistics from others with your disease, in all likelihood I believe you will. Whether that will be in 6 months or in several years, we do not know right now."

Dr. E then talked about the difficulty of dealing with an uncertain prognosis and how important it was for the family to continue to support and communicate with each other during this time. Dr. E offered to more actively coordinate Mr. Termillo's care, and rescheduled a follow-up appointment for Mr. and Mrs. Termillo for the next month. Mrs. Termillo agreed to be the primary person to dispense information coming from Dr. E. However, it was clear that the adult children did not entirely trust their stepmother to communicate all the information to them. Dr. E encouraged all the conference participants to communicate directly with him if they had questions that went unanswered. Dr. E said another family conference might be useful sometime in the future, and suggested that anyone at this conference could call and request it. Mr. Termillo appeared visibly relieved and thanked Dr. E for meeting with his family as he left the office.

Ongoing family dynamics and important unresolved issues are frequently highlighted around a terminal diagnosis. Having a shortage of time with a loved one can result in people wanting some resolution to long-term feelings or problems. As a primary care physician, facilitating this kind of resolution can be very meaningful for the patient and the family. For example, in the follow-up session with Dr. E, Mrs. Ter-

millio complained that her husband would not talk with her about his feelings. It turned out that this was a longstanding complaint of Mrs. Termillo's, and one she felt desperate to change in their final months together. By providing some support and communication guidelines, Dr. E was able to help the Termillos talk with each other about Mr. Termillo's illness. The couple then reported feeling closer to each other than they had in years. This was a case where primary care counseling was appropriate and effective. When the conflict is more severe and/or jeopardizes the medical treatment of the patient, a referral to a family therapist may be necessary. In these more severe cases, the goal may be to help the family pull together enough to work through the issues around the dying person.

"It would help me to discuss what kind of medical care you would like should you become extremely ill"

Treatment planning with patients and families around a terminal illness allows everyone to confront the reality of an impending death and to participate in and feel some control over the medical care process. Issues range from whether patients prefer another round of chemotherapy or surgery, to questions of hospice care or whether they wish to be resuscitated if they arrest in the hospital. Most often decisions made to limit medical treatment occur because further treatment is viewed as futile. These decisions can involve weighing the risk of premature death against the risk of prolonged, painful life without dignity. Often these choices should be understood as more ethical than medical (6), and should be made by the patient in consultation with family members.

Negotiations around treatment planning are easiest to accomplish when the physician has had a previous relationship with the patient and family. These discussions tend to be sensitive and emotionally charged. The physician can be most effective when he or she can draw on knowledge of the patient and family's history prior to any crisis. Ideally, prior to any serious illness the physician has discussed with the patient his or her wishes regarding medical care should a catastrophic accident or illness occur (6,7). While these discussions are useful with any patient, they are especially important with elderly patients, patients with chronic illness, or patients facing serious surgery. From an ethical perspective, any decision to limit treatment is best made by the patient, rather than the family or the physician, hence the value of the patient having a "living will." In spite of the compelling reasons to have such discussions with healthy patients, it is rarely done, perhaps because of time constraints in a busy practice, because of the physician's own denial

and avoidance of death, out of fear of causing depression or anxiety in patients, or for lack of interactional skills or experience (7). It is possible that having such a discussion will result in the patient becoming depressed, anxious, or resistant, so sensitivity, timing, and support are crucial to a successful interaction of this sort. The following are suggestions to facilitate the discussion of terminal treatment guidelines in the ambulatory setting:

1. While taking a routine genogram, ask "Who in your family do you turn to for support?" Follow up by asking, "Should you become seriously ill or injured, would that be the person you would like me to consult regarding treatment decisions?" (8).
2. At that point, or at a later session, ask about the patient's own wishes for treatment: "Although you are healthy now and we do not expect anything to happen, it would be helpful to know what your wishes are about your medical care should something catastrophic happen and you were unable to tell me what your wishes were at that time."
3. Be as specific as possible: "If your lung disease worsened so that I thought that you would never be able to breathe on your own again, I would you want to be on a respirator?" "If your heart stopped beating or you stopped breathing, would you want us to start your heart again or put you on a machine to breathe for you?"
4. Emphasize that the patient's input is helpful to you and allows you to be the best doctor you can be for him or her.
5. Encourage the patient to discuss his or her wishes with family members and other loved ones. "As difficult as it might be, it also might be useful to discuss these issues with your family while you are healthy and well."
6. Introduce the idea of a "living will." "Some people feel so strongly about what they do and do not want done for them in the event that they cannot make decisions, they have written living wills. Do you feel strongly about this?" If so, suggest a written living will, which should:
 - a. be as specific as possible regarding such possibilities as respiratory support, nutritional support, antibiotics, and resuscitation
 - b. name a surrogate or proxy who can have final authority, in consultation with other family members, to make unforeseen treatment decisions
 - c. contain the signatures of two witnesses
 - d. be updated yearly and/or prior to any hospitalization
 - e. be copied and given to family members and the primary care physician (9)

Know a patient's preferences is in everyone's best interest. One

ences about terminal medical care (maximal vs. comfort care) to be recorded in their charts. The researchers found that while not all patients could render a decision, the majority did have a preference they wished to be recorded (10). Most terminal patients, whether young or old, want to participate in treatment planning.

Mr. Rione was a 36-year-old man with a homosexual lifestyle who had been diagnosed HIV positive. With some difficulty, Mr. Rione decided to inform his family of his health status in the interest of trying to bridge some hard feelings that had arisen when he had revealed his sexual preference some ten years before. Mr. Rione used his primary care physician, Dr. Z, as a support and a sounding board during this period of time. As part of the process of discussing the uncertain course of this potential illness, Dr. Z also discussed how Mr. Rione, his lover, and his family could participate in treatment planning should he become symptomatic or seriously ill. Dr. Z described some of the potential treatments that are available for people who develop HIV syndromes, and solicited Mr. Rione's questions or concerns. She also emphasized that Mr. Rione was currently not symptomatic, may remain well indefinitely, and that research is very active in this area so that new treatments are likely to develop that are unknown now.

Once a patient becomes terminally ill, the hypothetical issues about treatment guidelines become a reality that must be faced. Hopefully, a family conference can be held to discuss these issues while the patient is still competent. The following are guidelines for a family conference focused on terminal treatment planning:

1. After a preliminary discussion with the patient, invite all family members the patient wishes to attend. Ask the family if they want to include their priest, minister, or rabbi in these discussions.
2. Join with all the participants. Then begin the conference by asking about less difficult issues, such as the current medical treatment, and move on to more highly charged issues, such as new prognostic information or questions about life-prolonging care.
3. Address the relevant medical issues, such as
 - What are the treatment options?
 - What does the treatment offer the patient?
 - What are the probabilities of success and failure?
 - Will the treatment cause additional illness? (11)
4. Solicit questions to help decide how much and what kind of medical information the patient and family want. It is easy to present medical information in a way that heavily influences the outcome of a patient or family's treatment decisions, so be as straightforward as possible and acknowledge personal biases that may affect the way the information is given. Be careful not to medicalize what are actually ethical issues.
5. Help the patient and/or family weigh potentially ethical issues against potentially undesirable ones.

comes

6. Help **both** patient and family stay focused on the patient's personal goals as primary in this process.

7. Work on being as nonanxious as possible in the room. These discussions are most frequently highly emotional for the participants, and benefit from facilitation by someone who is clear and calm.

8. Use clear, jargon-free language. Be a supportive, active listener. Track others' communications and clarify confusing statements made by any participant. Care needs to be taken to attend to communication issues in general because the likelihood of someone misinterpreting another's statements or intentions in this emotionally charged situation is high.

9. Model an ability to tolerate the ambiguity and uncertainty that accompanies all these decisions.

10. Communicate a willingness to sustain contact with the patient and the family regardless of their treatment decisions.

Many people are reluctant to limit medical therapy because they equate it with limiting care for the patient. Assure the patient and the family that all supportive care by the staff will be appropriately aggressive, including providing adequate pain control, attending to bladder and bowel functions, discontinuing unnecessary treatments, allowing lengthy or unlimited visiting hours, providing opportunities for the patient to talk (or be silent), and generally showing a high level of patient care (7). Miles suggests that patients or families that respond to discussions around treatment planning with "Do everything!" should be understood as saying "Slow down, give us more time to understand what you are saying" or "Show us that you care and won't abandon us at this time when our options are so profoundly limited" (11). Regardless of the decisions that are made concerning treatment, it is important to let the family know that their physician will stand by them and will not withdraw during their difficult time.

Dr. D requested a family conference after Mr. Mount's discharge from his third hospitalization for chronic obstructive pulmonary disease. The Mount family included the elderly Mr. and Mrs. Mount and their single adult daughter who lived with them. The family had a history of difficult medical and psychiatric problems: Mrs. Mount had cardiac arrhythmias and mild congestive heart failure. The daughter, Nadine, had perplexing neurologic symptoms as well as severe bulimia. The family was known for their resistance to medical intervention and their devotion to each other. In arranging the conference, Dr. D suggested the family bring the home health aide whom they had come to accept and trust. Dr. D invited the psychological consultant who had attended previous family conferences around other important family decisions.

The family arrived nervous but talkative with Mr. Mount in his wheelchair. Dr. D reviewed how Mr. Mount was doing at home. The patient reported that he was doing fine, only worried about the health of his wife and his daughter.

Mrs. Mount complained that her husband was too dependent and "could not try any small task without help. The daughter and the home health aide agreed. The consultant talked this over with Mr. Mount and discovered that he rarely even tried to walk because he was certain of failure, he feared being a burden to his family, and he felt to ask for help ahead of time was "unmanly." The family agreed with the consultant that Mr. Mount was a very proud man. They worked out some signals for him to acknowledge he needed their help early in a task so that he could "be less of a burden to the family in the end."

Following this problem-solving discussion, Dr. D asked Mr. Mount and the family for help in planning treatment guidelines for the next time he needed to go into the hospital. She asked Mr. Mount if he wished to go on a respirator if that was warranted. Mr. Mount was evasive and ambiguous in his answer, saying he did not think this would happen and if it did, his family could decide. Nadine left the room at this point, saying she had to go to the bathroom to vomit. Mrs. Mount refused to comment. With support from the consultant, she said she did not want to be responsible for her husband's treatment decisions because she had been the responsible party when her sister was critically ill and incompetent and it had been a very difficult role for her. Dr. D said this was why it was important to discuss these issues now. Mr. Mount agreed this experience had been difficult for his wife. With a lot of support and information, he was able to decide he would like to go on a respirator should he have respiratory failure, but that he did not want to have cardiac resuscitation should he arrest in the hospital. The daughter returned to the room during this discussion, and both she and her mother agreed to support Mr. Mount's decisions.

To summarize, the best situation occurs when a patient, in conjunction with family members, is able to express his or her preferences regarding treatment decisions. If the patient is unable to communicate and has not previously made his or her wishes known, the burden of responsibility falls almost completely to the family members. In one recent study 86% of families of incompetent patients made these decisions (12). Treatment decisions can be difficult for families to negotiate without considerable support and information from the medical staff. The physician may wish to keep in mind the following principles that guide a family conference for terminal treatment planning in which a patient is unable to participate:

1. Keep the care, comfort, and concern for the patient primary.
2. Include all available family members in the conference.
3. Hold the conference at the patient's bedside. Even if the patient is comatose, having the discussion with the patient there makes the decisions more real and diminishes family members' sense of guilt about having to decide about their loved ones' treatment.
4. Recognize the family's pain, and acknowledge the difficulty of the process.

Patients and families can respond to these discussions about limiting treatment in one of several ways. Bedell et al. found that families were most likely to choose to limit treatment, especially to write a Do Not Resuscitate order, under the following conditions: when the patient was in a coma or brain dead, when physicians and staff supported and reassured them that this was the appropriate decision, when they were assured that the staff would maintain the patient's medical care and comfort, when the patient had expressed a previous wish to the family regarding care, and when they were told the orders could be changed (12). The age of the patient, severity of the illness, and degree of patient suffering did not predict these family members' decisions.

Some family members clearly and unambivalently want "everything" done to keep their loved one alive. Others appear ambivalent, but unable to decide to limit treatment as they seem to view any restriction as abandonment or even murder. These family members may try very hard to get the medical staff to make these decisions for them or they may demand aggressive treatment because of their own feelings of sadness, denial, fear, anger, guilt, or abandonment. Many of these reactions change over time with a focus on making the patient's needs primary, so it is important to have discussions periodically both to update family members on any new medical information and to allow people to express changes that have occurred in their own thinking.

Mrs. Katz had been hospitalized for 10 days, but her fevers were still uncontrolled. This was her fourth hospitalization in the last six months. With dementia and Parkinsonism, complete incontinence, recurrent infections and deep decubiti ulcers unsuccessfully treated with surgery, death seemed inevitable to her physician and hospital staff. Dr. S initiated a discussion of limiting treatment with the patients' two daughters at their mother's bedside. Adele, the younger daughter, had been unusually attentive and involved. She was always available, left two or three phone numbers, visited daily, and made lists of questions and suggestions about her mother's treatment. Observing this painful daily decline, she reluctantly came to accept her mother's impending death as a certainty and favored writing Do Not Resuscitate orders. Her sister, Robin, was a much less frequent visitor and was often unreachable because of her long and unpredictable work hours. Her ideas were relayed to Dr. S by Adele, accompanied by barely disguised anger, as Robin maintained that she could not "give up on Mom."

When Dr. S finally met with Robin and Adele, Robin expressed bitter frustration at a previous physician's lack of consideration in never consulting her about her father's care the previous year, when he was "allowed to just die." Until Dr. S could have a family conference and meet with these daughters together, he was unable to resolve the issues around treatment planning for their mother. By encouraging them to talk together about what their mother have wanted and what was in her best interest, Robin slowly agreed that treatment was the best option available. Dr. S encouraged both

"I need to inform you that your loved one has died"

Notifying family members about the death of a loved one is a difficult, stressful task. Direct, sensitive communication makes it more likely family members will hear the message clearly. Prior discussions with a family about an expected death make this situation generally easier to deal with than that of an unexpected death. The following are suggestions for notifying the family about a death:

1. Encourage the family to be present at the time of death if at all possible. One study demonstrated that a majority of family members were grateful to be present during a resuscitation attempt for their relative (13). Any action that helps family members participate in and acknowledge their loved one's death may be useful.
2. When the family is expecting the death of one of its members, ask how they would prefer to be notified if they are not present.
3. Notify the family immediately at the time of death.
 - a. With an expected death, call on the family as previously agreed upon.
 - b. With an unexpected death, ask the family as a whole to come to the hospital and discuss the events leading up to the death.
4. While being sympathetic and sensitive, avoid euphemisms. Use the words "death, dying, and dead" rather than "passed away" or other colloquial sayings.
5. Say "You have my sympathy" rather than "I am sorry," which could be construed as an apology.
6. Give the family the opportunity to view the body and say their good-byes.
 - a. Arrange for the viewing to occur in a private room.
 - b. Make sure the body has been cleaned and prepared, so that wounds have been dressed, blood stains removed, and the body draped and placed in an appropriate position.
 - c. Offer to have a member of the health care team stay with the family, especially if only one member is present.
 - d. Allow them to remain with the deceased as long as they wish (14,15).
7. Meet with the family.
 - a. This may occur before or after the viewing. Either way, it is an important step in showing concern and facilitating a healthy early grieving process.
 - b. Provide information about the cause of death. Solicit and answer any questions.
 - c. Make any requests for autopsy or organ donations as time allows.

- d. Use active listening skills. Expect and tolerate expressions of intense emotions, especially with a family who learns of an unexpected death. Do not exclude family members who become very upset or emotional. Avoid psychotropic medications in this situation.
- e. Make yourself available as a support for the family. Suggest a follow-up meeting to discuss autopsy results or questions about the deceased that are likely to arise in the future.
- f. Remind the family to call their funeral director.
- g. Encourage the family to include children, especially those over 5 years old, in the funeral and other family gatherings.
8. Send a sympathy card to the family, or attend the wake or funeral.
9. Telephone the family 1-2 weeks after the death to inquire about them, answer any questions, and schedule a follow-up appointment.

"What did I do wrong?"

One of the most difficult aspects of dealing with a patient's death is the physician's own feelings. Though in a different and much less intimate role than that of a family member, the health care provider may also experience feelings of sadness, loss, anger, or guilt. In addition to facilitating the grief process for the family, the provider also needs to attend to his or her own grief and acknowledge his or her own feelings. Rituals such as saying good-bye to the deceased and attending the funeral when possible (16) allow for the emotional side of being a doctor to be nourished and utilized.

Especially with an unexpected death, or the death of a young person, the physician usually examines the patient's history and course of treatment to determine any professional failures on his or her part. This process can be important and useful if it is seen as an opportunity to learn from the careful examination of a case rather than to perpetuate perfectionist, superhuman standards for providing medical care. At those times when mistakes have been made, it is important to face them squarely and create opportunities for confession and forgiveness (17). Discussing the case with trusted colleagues can be both educational and cathartic, especially if uncertainty and guilt remain prominent feelings over a period of time after a patient death (3).

"To feel pain and sadness at this time is a normal, healthy response"

Primary care grief counseling offers significant opportunities for medical providers to encourage healthy grieving and prevent pathological or

tant (18). Even in these cases, the usual grief response is time-limited and somewhat predictable in its phases. Normal grieving is characterized by intellectual and emotional awareness of the loss and feelings of guilt, stress, pain, anger, and hostility (19). Grief is typically a cyclical process in which all these feelings may be present at any time, but certain feelings may dominate at different points in the cycle. The acute phase begins with the notification of death and is characterized by emotional shock. This phase typically lasts for up to two weeks. Depression and somatic symptoms are common and persist into the second phase, characterized by rumination over memories of the deceased. During this phase, people may withdraw and become introverted as they examine what the recent death means for their own life. This process typically takes from 3-6 months. The third and final phase is the resolution phase. At this time, somatic symptoms and preoccupation with the deceased lessens. Bereaved family members begin to plan for the future and participate again in activities that were an important part of their lives prior to the death. The resolution phase is punctuated by the anniversary of the loved one's death. After this period, which often involves a temporary increase in grief or symptomatology, most people are able to move on.

The following are principles for primary care grief counseling:

1. Schedule an office visit at 6-8 weeks with interested family members to review the death and the autopsy results.
2. Encourage family members to talk about the circumstances surrounding the death, recall memories, and openly discuss feelings of sadness, anger, and guilt. Give them permission to grieve.
3. Inquire about any significant changes in financial status. Settling an estate, the loss of income, and the lack of experience managing money can intensify the grieving process.
4. Normalize signs of grieving, such as crying spells, lack of energy, and preoccupation with the deceased. Tell the family that normal or uncomplicated grief typically takes at least a year for the active phase to resolve.
5. Avoid the use of psychotropic medication, such as sedatives or hypnotics, except in very unusual circumstances. A sedated person at a funeral may not be able to participate or even remember this important time. Starting antidepressant, anti-anxiety, or antipsychotic medications are rarely indicated during bereavement.
6. Monitor the medical status of the recently bereaved closely as research indicates that the bereaved are at higher risk of serious illness and death. (See Chapter 2.) Encourage family members to come in for a health evaluation at 3 months to assess any increased risk for illness or delayed difficulties with grieving.
7. Refer interested family members to community-based self-help sup-

Table 14.1. Signs and Symptoms of an Unresolved Grief Reaction

1. Prolonged, severe clinical depression (that is, a pervasive sense of worthlessness and self-blame lasting longer than 12-18 months)
2. Prolonged social isolation, withdrawal, or alienation
3. Emotional numbing in which the patient largely denies an emotional reaction to the loss, resulting in a kind of wooden or flat emotional presentation
4. An inability to cry
5. Talking as if the dead person were still alive
6. Persistent compulsive overactivity without a sense of loss
7. Persistence of a variety of physical complaints, such as headaches, fatigue, dizziness or multiple injuries
8. Prolonged identification with the deceased and prolonged acquisition of symptoms belonging to the illness of that person
9. Extreme, persistent anger (may be directed at the physician)
10. Alcohol or drug abuse, persistent requests for sedative or narcotic medications
11. Marital or family problems (can be especially prominent after the death of a child, but not uncommon after the death of an elderly parent)
12. Work or school problems

SIDS children, or any of the many other illness-focused support groups. Support and information from those who have experienced a similar loss themselves can be extremely helpful to the bereaved.

8. Monitor family members for signs of unresolved grief reaction (19-21). (See Table 14.1.) Refer if necessary.

Prolonged and extreme reactions to grief are themselves dangerous and necessitate referral to a specialist. Such a referral is best made to both the person with the symptoms and that person's family. Referral may be made for evaluation, bereavement counseling, psychiatric treatment, or family therapy, as is appropriate.

The following example describes a close married couple from the time of the acute phase of the husband's illness to the year following his death.

Mrs. Stowe had cared for her husband for over 20 years. He was blind and suffered from Alzheimer's Disease. Over the previous year he had become increasingly difficult to care for; he became incontinent and began wandering at night. His normally cheerful mood changed gradually as he became more irritable and resisted any assistance. After being struck by him on several occasions, Mrs. Stowe decided she could no longer care for him at home. She had kept him with her in their small apartment with few services long past the point when most families would have institutionalized a demented elderly member. She herself was 84 years old, and the physical and emotional stress of caring for her husband was beginning to affect her health. Her three children had begun encouraging her for several years to arrange for placement.

Because the couple had significant savings, Mr. Stowe was placed in a nursing home within a month of Mrs. Stowe's decision. She became

encouraged her to visit him regularly and ventilate her feelings. She spent most of her day with her husband in the nursing home, but continued to feel that she had betrayed him. Now she felt she had nothing worthwhile to do with herself.

Several months after his admission, he suffered a massive stroke and died within a week. Mrs. Stowe became increasingly depressed over the next 6 months, grieving over his death and feeling that her life, which had been spent caring first for her children and then for her husband, was now worthless. Her family tried to cheer her up, which only made her feel that they did not understand her grief. Efforts to get her involved in social activities in the apartment house where she lived were unsuccessful because she viewed any social activities as "a waste of time."

A month after Mr. Stowe's death, Dr. C met with Mrs. Stowe, her children and several of her grandchildren, who were concerned about Mrs. Stowe's emotional state. Dr. C explained that the intensity of Mrs. Stowe's grief was testimony to what a special relationship the couple had, and that to give up that grief too soon would seem to Mrs. Stowe to be dishonoring her husband. He encouraged Mrs. Stowe's children to share their memories of their father and how much they also missed him with their mother.

Dr. C met with Mrs. Stowe every 3 months for the first year of bereavement. At 6 months, he began to encourage her to get involved in volunteer work where she could help and care for other people. A year after her husband's death, Mrs. Stowe's grief and depression had begun to lift. She was doing some volunteer work at a local hospital and felt she had found some meaning in her life. Her spirits were improved though she continued to miss her husband deeply.

Grief typically sends "shock waves" throughout a family system (22). The goal of primary care management of terminal illness, death, and grieving is to channel these shock waves so they can have a restorative effect, and to monitor their influence to prevent future disruption or symptomatology.

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PROTOCOL

Talking to Patients and Families about Terminal Illness, Treatment Planning, and Grief

Communicating a Terminal Diagnosis

1. Communicate directly to the patient about the diagnosis, the care, and the prognosis of the illness.
2. Avoid giving an overly optimistic or overly pessimistic prognosis. Be honest and straightforward about the information as you know it.
3. Look the patient in the eye and speak calmly. Repeat the message several times.
4. Avoid arguments over the diagnosis, or other maneuvers that distract from the message itself.
5. Set up another appointment to answer questions that will inevitably arise when the initial reaction wears off.
6. Repeat this process with the family present.
7. Allow people their depression or anger rather than trying to reassure them or brighten their mood.
8. Meet regularly with the patient and family to discuss care, prognosis, and individual's emotional reactions, even when the medical care is managed by a specialist.

Treatment Planning for a Terminal Illness

A. Discussing terminal treatment guidelines in the ambulatory setting

1. While taking a routine genogram, ask "Who in your family do you turn to for support?" Follow up by asking, "Should you become seriously ill or injured, would that be the person you would like me to consult regarding treatment decisions?"
2. At that point, or at a later session, ask about the patient's own wishes.
3. Be as specific as possible.
4. If your state has a law regulating "Do Not Resuscitate" orders, briefly describe the law to the patient.
5. Emphasize that their input is helpful to you and allows you to be the best doctor you can be for them.
6. Encourage the patient to also discuss their wishes with family members and other loved ones.
7. Discuss the idea of a "living will."

B. Guidelines for terminal treatment planning at a family conference

1. After a preliminary discussion with the patient, invite all family members the patient wishes to attend. Ask the family if they want to include their priest, minister, or rabbi in these discussions.
2. Join with all the participants. Then begin the conference by asking about less difficult issues and move on to more highly charged issues, such as life-prolonging care.
3. Address the relevant medical issues.
4. Solicit questions to help decide how much and what kind of medical information to provide.
5. Help the patient and/or family weigh potentially good outcomes against potentially undesirable ones.
6. Help both patient and family stay focused on the *patient's* personal goals as primary in this process.
7. Work on being a nonanxious presence in the room.
8. Use clear, jargon-free language. Be a supportive, active listener.
9. Model an ability to tolerate the ambiguity and uncertainty that accompanies all these decisions.
10. Communicate a willingness to sustain contact with the patient and the family regardless of their treatment decisions.

C. Principles for terminal treatment planning at a family conference in which a patient is unable to participate

1. Keep the care, comfort, and concern for the patient primary.
2. Include all available family in the conference.
3. Hold the conference at the patient's bedside.
4. Recognize the family's pain, and acknowledge the difficulty of the process.

Notifying the Family about a Death

1. Allow the family to be present at the time of death if at all possible.
2. When the family is expecting the death of one of its members, ask how they would prefer to be notified if they are not present.
3. Notify the family immediately at the time of death.
4. While being sympathetic and sensitive, avoid euphemisms. Use the words "death, dying, and dead."
5. Say "You have my sympathy" rather than "I am sorry," which could be conveyed as an apology.
6. Give the family the opportunity to view the body and say their good-

7. Meet with the family.

- a. Before or after the viewing, meet with the family to show concern and facilitate a healthy early grieving process.
- b. Provide information about the cause of death. Solicit and answer any questions.
- c. Make any requests for autopsy or organ donations at this time. Clarify the reasons for the request, particularly when there is uncertainty about the diagnosis.
- d. Use active listening skills. Expect expressions of intense emotions.
- e. Make yourself available as a support for the family. Offer to have follow-up meetings, either to discuss autopsy results or questions about the deceased that will likely arise in the future.
- f. Remind the family to call their funeral director.
8. Send a sympathy card to the family, or attend the wake or funeral.
9. Telephone the family 1-2 weeks after the death to inquire about them, answer any questions, and encourage any necessary follow-up.

Primary Care Grief Counseling

1. Schedule an office visit at 6-8 weeks with interested family members to review the autopsy results.
2. Encourage family members to talk about the circumstances surrounding the death, recall memories, and openly discuss feelings of sadness, anger, and guilt.
3. Inquire about any significant changes in financial status.
4. Normalize signs of grieving during the first year, such as crying spells, lack of energy, and preoccupation with the deceased.
5. Avoid the use of psychotropic medication, such as sedatives or hypnotics, except when previously prescribed or in very atypical circumstances.
6. Monitor the medical status of the recently bereaved. Encourage family members to come in for a health evaluation at 3 months to evaluate any increased risk for illness or delayed difficulties with grieving.
7. Refer interested family members to community-based self-help support groups for those who have recently lost a loved one.
8. Monitor family members for signs of unresolved grief reaction. Refer if necessary.

Delivering Bad News to Patients and Their Families

*It's an unenviable task,
but you and your patients
can benefit from your
doing it well.*

Ronald E. Waldrige, MD
and Ronald E. Waldrige II, MD

I had my first experience with delivering bad news to a patient as a third-year medical student on my internal medicine rotation. My team had admitted a young man with new-onset seizures. His CT scan was consistent with toxoplasmosis, and not surprisingly, he tested positive for HIV. When the lab results came back, my supervising resident suggested I tell the patient because I "knew him better." Needless to say, I stumbled through the interview and found myself woefully inept at answering his many questions. I decided then that I would never again enter that situation without having thought through any questions the patient might ask, and their answers.

I recently found myself in a similar situation as an intern in family practice residency when I admitted a child with a lethal heart defect into the neonatal intensive care unit. The attending physician on my service, explaining that she "did not feel comfortable with these situations," asked if I would please speak to the family. I spent some time reading and talking with the pediatric cardiologist to familiarize myself with the disorder, its prognosis and treatment options. I then felt prepared to talk with the family about withdrawing support from their unfortunate child. The grief-stricken family was understandably devastated by the news. On this occasion, I felt prepared to handle the medical questions, but I was not prepared to handle the onslaught of emotion brought on by the bad news.

Looking back, with more experience under my belt, I think of how I might have handled these situations differently. I've also come to realize that delivering bad news to patients and their families is a stress-provoking endeavor for health care professionals, and perhaps better training in this area could relieve some anxiety. With this awareness, I enlisted the help of my father, a practicing family physician with 28 years of experience, and after reviewing the literature, we developed a model for delivering bad news. —

Ronald E. Waldrige II, MD



BILL FIRESTONE

CME COVERED IN
FPM QUIZ

What is bad news?

In a wonderful book, Robert Buckman, MD,¹ describes bad news as "... news that drastically alters the patient's view of her or his future." In sharing information, be it good or bad, we must be sensitive to the potential impact on the patient. It is important to remember that what physicians view as benign, or even good news, may be terrible news to the patient; many

Ronald Waldrige, MD, is a family physician in private practice in Shelbyville, Ky. His son, Ronald Waldrige II, MD, completed his residency last summer at Carolinas Medical Center in Charlotte, N.C. He has since returned to his hometown and joined his father in practice.

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► A physician's and patient's ideas about what constitutes good news, bad news or something in between may differ.

► Delivering bad news is difficult for physicians, in part because it's contrary to their desire to make patients feel better.

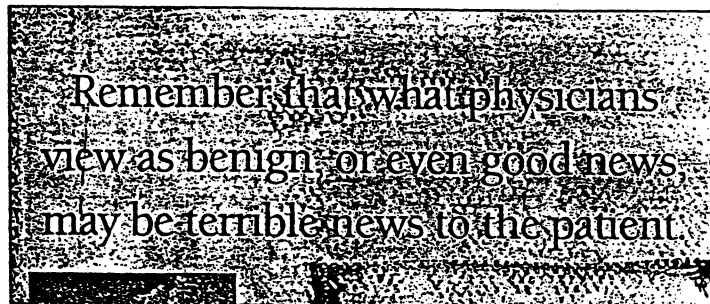
► Experience, not medical school and residency training, teaches skilled doctor-patient communication.

► To prepare for the conference, study the facts, carefully choose the setting and the time and determine who should be present.

physicians have eagerly announced, "You're pregnant!" only to find the patient distraught. As physicians, we should also be sensitive not to downplay news such as the diagnosis of diabetes. Because we see diabetes all the time and may have patients who have a benign course with it, we tend to become somewhat jaded. However, we must bear in mind that in delivering bad news, we are telling the patient he or she is "sick," and the patient may have many negative feelings about the diagnosis.

Why is it so difficult?

Many factors make delivering bad news hard for physicians. We like to make people feel better, but hearing distressing news almost always makes patients feel worse. The possibility that patients will blame us for their misfortune adds to the



Remember that what physicians view as benign or even good news may be terrible news to the patient.



difficulty. Another challenge is that the experience makes us keenly aware of our own mortality. It may also place us in a

position of admitting uncertainty.

Furthermore, medical school and residency training do an inadequate job of preparing us for this difficult task. Medical education emphasizes performing the physical exam, developing a differential, arriving at a diagnosis and knowing what treatment is indicated. None of these skills come into play in the family and patient conference. Rather, skilled doctor-patient communication must be learned through experience. As Sir William Osler once said, "Medicine is learned by the bedside and not in the classroom." By developing the following skills, we can minimize the emotional trauma that delivering bad news causes us and our patients.

Preparing for the conference

The key to a successful interaction between the physician and the patient and family is preparation. Remember that delivering good news is spontaneous ("Congratulations, Mr. Smith. You have a healthy, beautiful baby!"), but delivering bad news requires planning. The following steps should guide you:

1. Get the facts straight. Familiarize yourself with the chronology of events, the medical facts of the case and the diagnosis, treatment options and prognosis.

2. Choose the appropriate setting. Ideally, it should be a face-to-face encounter (not delivered over the phone) carried out in a private place (an office, conference room or patient's room) where there won't be undue distractions.

3. Determine who should be present. This can be done, for example, by telling the patient that you have received his biopsy results and that there is cause for concern and then asking whether he would like to have his loved ones present before discussing the results. If others are to be

included, making sure that all the requested participants are in attendance will spare you from going over the news on several occasions. You may be able to ask one family member to be responsible for assembling the entire group.

4. Decide when to conduct the conference. It should be held as soon as possible, while allowing time for the individuals that make up the patient's support structure to come together. Ideally, you and the patient should both be rested and alert, and you should build an adequate amount of time for discussion into your schedule.

Beginning the conference

Before the conversation begins, make a point of introducing yourself to each person participating in the conference. This common courtesy may save you the embarrassment of addressing someone in the vicinity who is not meant to be included in the conference. Sit down so you are at or below the patient's eye level

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► In telling the bad news, it's important to be truthful, avoid using jargon and not dash the patient's hope.

► After telling the news, allow the patient some time to process the information, and help him or her to clarify the questions.

► Expressions of empathy and emotion by the physician can benefit both patient and physician.

► When answering the patient's questions, be truthful, compassionate and willing to admit when you don't know the answer.

so as not to appear threatening or dominant. Have some tissues handy. Hold phone calls, and if possible, have a colleague handle your pager to limit distractions. You might also consider touching the patient during the conference. Some physicians are uncomfortable with this idea, but we feel it is very important. Placing your hand on the patient's shoulder establishes contact, transmits concern and empathy and can be therapeutic in its own right.

Delivering the news

We developed the following mnemonic device to help us remember the important components of the conference with patient and family. It works well with any type of doctor-patient interaction. Because of the imperative to listen and hear what the patient is really saying, we've made the mnemonic "TO HEAR":

- Tell the bad news,
- Offer an opportunity for information to soak in and questions to be asked,
- Help the patient to elucidate questions,
- Empathize with the patient,
- Answer questions,
- Reinforce the information given.

Tell the bad news. Before conveying any information, find out how much the patient knows and how much they *want* to know. Some patients will tell you that they would rather not know if they have cancer, for example, and we feel it's

begin the emotional healing process. Some physicians may be concerned that telling a patient of a terminal condition may push them closer to death, but this has not been shown to be the case.²

Family members may implore you not to tell their loved one the bad news ("Please don't tell Grandma she has cancer; it will devastate her"). Remind them that their grandmother is competent, that she has employed you to take care of her and that she will be told the diagnosis. This may also be a good time to explain to the family that unless their grandmother wishes, you won't be providing the family with any further information regarding her condition.

Remember to avoid medical jargon when speaking with the patient and family. After spending years in medical school and postgraduate training learning an entirely new vocabulary, it can be difficult to translate your thoughts to layperson's terms. But explaining things so the patient can understand them will help you to establish a good therapeutic alliance and will help the patient to begin the healing process.

While being truthful, you should also try to keep hope alive. Even if it is the slimmest of hope, it may be all the patient has to keep going. Besides, as physicians know, miracles do happen.

Another important guideline is to deliver the bad news in a step-wise fashion, proceeding from the least threat-

Don't feel compelled to talk incessantly. Silence can be golden.

important to respect their wishes. Oftentimes, these patients will change their mind.

For those patients who want to know about their condition, make sure you tell the whole truth, and don't sugarcoat it. Patients can handle the truth, and they need to hear it. By fully understanding the reality of their medical condition, patients can make better decisions regarding treatment and can

ening to the most stress-provoking news. Following a chronological path is often an effective approach. Here's an example:

"Ms. Jones, as you remember, you came to me when you first noticed the lump in your right breast. After examining you and checking a mammogram, we decided that indeed there was a small mass in the breast. You then went to the surgeon to have the tumor removed. I have now gotten the report back from



laboratory, and it shows that there are cancer cells in the tumor that was removed ..."

Offer an opportunity for information to soak in and questions to be asked. Don't feel compelled to talk incessantly. Silence can be golden, and words often prove useless at soothing pain. Often, the physical presence of the physician and time to process what they have just been told are what the patient needs most.

Help the patient to elucidate questions. When the patient or a family member asks a question, avoid jumping right into your answer. Try to help the patient clarify what they really want to know; one technique involves having the patient restate the question. A colleague conveyed the story of a patient who had just been told that a breast mass was cancerous. The patient responded by asking, "How long do you think it will be ...?" The doctor promptly launched into a lengthy discussion of prognostic factors and treatment modalities. Noticing a puzzled look on the patient's face, he paused for a moment. The patient then explained, "I mean how long until I can return to work full time?" By attempting to answer a perceived question, the doctor made the initial interaction awkward and confusing for the patient. Do not assume that you and the patient have the same agenda; you must begin by hearing the patient's concerns.

Empathize. After determining what the patient is asking, take a moment to empathize with his or her concern: "It must be quite overwhelming to be told such bleak news"; "I can understand your worries of pain associated with the treatment"; "Many of my patients share your feelings of disbelief when given such a diagnosis." Do not be afraid to show emotion. It can be good for the patient and the physician. It shows the patient that you are a caring and feeling individual, and it allows you to release some of the stress associated with these situations. A caveat to young physicians: You must find a middle ground between getting too close to your patients and appearing cold and aloof in your interactions with them. You must be able to maintain composure in these difficult situations and cope with their prevalence.

Answer questions. In answering the patient's questions, your preparation and discussions with other specialists will pay off. Always answer the question truthfully and with compassion. Don't be afraid to say, "I don't know." Physicians tend to have difficulty admitting that they do not have all the answers. However, it is much better to explain, "That is a very good question, but I'm not sure I know the answer," and promise to find the needed information

Do not assume that you and the patient have the same agenda. Begin by hearing the patient's concerns.



rather than to make up an answer that could be damaging in the future. When patients ask about prognosis, it has been shown that they want to know the mortality or morbidity rate associated with their condition.³ While sharing this information, keep in mind that even if the chances of survival are slim, you do a disservice to patients if you dash their hope. In answering questions, be truthful and do what you can to keep hope alive!

Reinforce information given. In receiving bad news, the patient will only be able to absorb small bits of information. Try to get a read on the patient's understanding of what you have said. Reinforce the important points, and remember it is usually not imperative to give the patient all the information at once. The patient's body language and facial expressions will give you clues as to how much information you should cover in the first conference. By watching and listening, you'll get an idea of how much a patient is assimilating.

Closing the conference

In drawing the conference to a close, tell the patient your plan for follow-up. Let

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◀ After answering the patient's questions, reinforce key

points and try to determine how much the patient has understood.

▶ At the end of the conference, tell the patient how you plan to follow up and that you'll be available to address further questions.

▶ Make sure someone sits with the patient until he or she is composed. Don't leave the patient alone after the conference.

▶ Family physicians are well suited to coordinate the care of critically ill patients.

the patient know you will be available to address further questions, and recommend that the patient and family members write down questions as they arise. This is also a good opportunity to mention other sources of support available to the patient, such as the hospital chaplain, social worker and support groups. We recommend touching the patient again before leaving to reinforce your compassion and to connect with him or her before departing. Never leave a patient alone after delivering bad news. If family members can't be present, arrange for a nurse or aide to sit with the patient until he or she is composed, if you are unable to stay yourself.

Parting thoughts

In researching this topic we did some reading about the discipline of thanatology, which is concerned with the humanitarian care of critically ill patients and their families, and the coordination of a multidisciplinary team of professionals in medicine, theology, social work, psychology, ethics and law. Given our knowledge of the family, our understanding of the biopsychosocial model of disease, our grasp of the various resources on which to draw for support and the compassion for patients that led us to family practice, who better to coordinate this type of multidisciplinary care than family physicians?

On the subject of hope, Osler once said, "Nothing in life is more wonderful than faith — the one great moving force which we can neither weigh in the balance nor test in the crucible." If you practice medicine long enough, you will undoubtedly encounter medical miracles that cannot be explained with medical science. If a patient is inclined to believe in alternative medicine or religion, the physician should not be the one to take this away. Some physicians may want to discuss religious beliefs or even pray with the patient. You can use the patient's spiritual beliefs as your ally in helping the patient through this difficult time.

Patients and families often retain vivid memories of the conference in which they learned bad news from their physician. By preparing for this task, you can help make their memories less distressing. While the interaction can be

Suggested reading

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difficult, you can derive some satisfaction in doing it well. "Delivering" used in combination with "bad news" has an unfortunate connotation. We feel that "sharing" better describes the approach that family physicians should take when there's bad news to be discussed. Your patients and their families will appreciate your heartfelt compassion, and you can be left with the thought that though it is an unenviable task, you do it better than anyone else. FPM

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HOW DO YOU SAY, "THE PATIENT DIED"?

STFM 26th Annual Spring Conference
April 24 - 28, 1993

Gene M. Bont, M.D., Ronald G. Nathan, Ph.D.,
Mary F. Smith, M.S.W., Ph.D., and Phyllis F. Bont, F.N.P.
Albany Medical College, Department of Family Practice

INTRODUCTION

Telling the family that a loved one has died is an important but often uncomfortable and unpopular responsibility.

At the moment of a patient's death, one's responsibility and focus shifts to the family members. Family survivors are at risk for anything from immediate syncope to life-threatening guilt. Survivors of spouses who die suddenly are at significantly higher risk for later maladjustment and unresolved grief than those of spouses whose deaths were expected.

The physician usually experiences a variety of emotions after a patient's death and may also be exhausted. Feelings of failure and guilt may compete with sadness over one's own recent losses or anger. These feelings may inhibit or overwhelm the physician in the face of telling the family that the patient has died.

Sudden death generally requires more physician time and skill. The following suggestions make clinical sense and are repeated frequently in the literature.

PHYSICIAN PREPARATION

Physicians should prepare themselves to discuss the death with the family. Delaying too long can increase the family's anxiety. Rushing out to tell the family can result in an awkward presentation.

Anticipation is one of the most healthy and powerful defense mechanisms for you, your staff and your patients. If you do not know the family, get data on the survivors from anyone who has had contact with them. Review the chronology of the event and the patient's name so you can be knowledgeable and personal about the news. Prepare yourself for a range of family responses such as anger, sadness, relief, guilt, accusations of malpractice, no reaction, bickering among members, avoidance, etc.

Whenever possible, present the news yourself, but share the task with a team member so you can give each other emotional support and the other member can remain longer with the family to repeat and clarify the information presented.

FAMILY PREPARATION

Many times, the family must be contacted by phone when a patient dies unexpectedly. The Critical Notification Approach, rather than the Direct Notification Approach, is preferred by most physicians and adults. This approach includes telling the family that the patient was critically ill and asking the family to come to the hospital as soon as they could safely do so. This hopefully prevents some of the trauma of shock. In addition, the travel time helps family members gather together for support and brace themselves for the worst. It also gives the health team time to call the coroner and chaplain, locate a private setting, prepare the body for viewing and obtain the paperwork for autopsy and organ donation.

PREPARING THE BODY

The body of the deceased should be prepared for viewing, by surgically dressing disfiguring wounds and removing life support equipment. These tasks can often be delegated to another member of the health team.

The importance of viewing the body unless terribly disfigured has been established, especially for parents of a dead child. After you deliver the news, encourage the parents by asking, "Would you like to view the body now or later?" rather than asking if they would like to do so. The doctor should prepare the family for what

you'll see in terms of wounds or injuries and accompany viewers of the body if at all possible.

DELIVERING THE NEWS

When presenting the news, both the physician and family should be seated so as to convey that the physician can spend the time needed to be of help.

Many physicians are tempted to explain, "One of the most difficult things I have to do as a doctor is to tell someone that..." Unfortunately, this amounts to a veiled plea by the physician for mercy, gratitude, or comfort and often detracts from the support the family needs.

Be simple and direct. Most physicians and patients prefer an announcement of automatic news, when presented in person, to be given immediately or very soon after the start of the conversation rather than leading up to it gradually. It is often best to state only one or two of the major events leading to death before simply and directly stating that the patient died. Use the patient's name and repeat at least twice that he or she has died.

In the case of suicide, use the word "suicide" in talking with the survivors. Offering the opportunity to see a therapist to help them adjust is far better than avoiding the word suicide and reinforcing the stigma and denial.

Avoid the temptation to medicalize and intellectualize. It is necessary to give some medical information but be cautious of overdoing it.

Touch family members, if you're comfortable doing it. This most basic and responsive form of communication can be very powerful.

Avoid apologies such as "I'm sorry," when informing the family because the survivors may pursue the legal implications of what sounds like an apology. The alternatives, "Everything was done that could have been done" and "You have my deepest sympathy" may be more useful.

To prevent unnecessary anguish about the patient's last moments, you can add, "The patient was unconscious," "the patient was unaware of his predicament" or "he was oblivious to pain".

Accept and permit tears as a normal response. If uncomfortable or near tears, the physician might do better to join with the family's weeping than to offer platitudes like, "At least...". In an effort to comfort, some physicians tell the grieving, "You'll get over it." Better, perhaps, to offer a more realistic hope by saying, "Time will ease the pain." Wait for questions. Questions often address preventability, pain, last words, and other concerns. They also give the doctor data about the family's denial or readiness to move on to other tasks of grieving or disposition.

Use of sedatives - Family members will sometimes ask for medications to get them through their grief. In general, tranquilizers should be avoided because the long use of drugs only delays the grief process and may lead to unresolved grief. If medically indicated, sedatives should be given for only a few nights.

As you inform the family, it is important to be prepared to handle syncopal episodes. Some recommend those members of the family be taken to the ER and examined by another physician, so that you can continue comforting the family.

AUTOPSIES

Near the end of the process, the physician should ask about an autopsy. Research has shown that many families who are not asked, decide later that if only an autopsy were conducted, some important questions could have been answered.

Explain the benefits including finding the cause of death, the preventability of death, the heritability of the disease, and other information that might help future patients.

Ask the family how they feel about an autopsy. Acknowledge reservations, but inform them that most spouses who agreed to autopsy feel that it was beneficial to

themselves and/or others. If the family is unsure or parents are conflicted, give them some more time.

Where there are strong objections or in cases where little can be learned by autopsy, the matter should not be pursued.

ORGAN DONATION

Organ donation should also be discussed near the end of the process. This benefits both those in need of the organs as well as the survivors. Such a donation can help make the loss more acceptable by offering a way to find some potential meaning to the tragedy and/or a way to relieve unresolved guilt.

FOLLOW-UP

Survivors often want and need subsequent contact with the physician. Always schedule a follow-up appointment in your office.

Attend funeral services but only if you feel you want to go. This can be very comforting to the family. Cards and phone calls by the physician or staff are appreciated.

Aftercare can address important unresolved issues thereby preventing somatization disorders or their escalation. Potentially suicidal depression can also be detected in such visits. Referrals to self-help groups, particularly for grieving parents can be given at any time in the process.

Suggest to the family it may be best to avoid any quick decisions or permanent changes right away. When a surviving spouse is forced to adjust to a smaller apartment too soon or someone cleans out the deceased person's belongings without the spouse's active involvement, anger and other unresolved grief reactions often result.

The following are some examples of statements taken from a number of sources that you can use in your follow-up contacts with family members:

"You will need time for the grieving process. Do not be in a hurry to get over it. Allow nature to take its course."

"Get plenty of rest."

"Remember that your powerful and overwhelming feelings of pain will ease with time."

"Everything was done that could have been done."

"Share your pain with those you feel comfortable with and accept support when it is offered."

"Surround yourself with plants, animals and friends."

"Avoid major decisions, and do not rely on alcohol, tobacco, or drugs."

"Keep a diary and record your memories and feelings about your loved one, past struggles and successes."

"Prepare to meet new friends, make new relationships, and use creative urges to write, build, paint, play music, plan a trip, reorganize or redecorate you home."

"Expect holidays and anniversaries to be difficult for a while as they will bring up painful feelings and memories."

"You have my deepest sympathy."

"Time will ease the pain."

"Please call if you have any questions or concerns. I am here for you as your physician."

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DEATH NOTIFICATION SCRIPTS - A FACILITATOR'S GUIDE

Eugene M. Bont, M.D., Ronald G. Nathan, Ph.D.,
Mary F. Smith, M.S.W., Ph.D., and Phyllis F. Bont, F.N.P.
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DOCTOR 1 (ER Physician dealing with surviving friends)

Two people traveling together to this meeting were involved in an auto accident. Both were taken to your ER department. One person sustained minor injuries, was treated, and was waiting for her friend to be treated and released. The companion, however, died of her injuries 2 hours after being brought into the ER. You must discuss this death with the traveling friend, who is upset because of the accident and also tired from the waiting. You must also determine who the next of kin is for the deceased person and who will make the call to notify the family.

SURVIVOR 1 (Guilt-ridden friends)

As the traveling companion, and driver of the auto, you feel guilty about the accident even though it apparently was not your fault. You are in shock when you hear the news and you can't decide if you as the friend or the doctor should be the one to notify the husband of the accident and death.

DOCTOR 2 (ER Doctor)

During your emergency room shift, an ambulance brings in three head-on auto accident victims dead-on-arrival. You've used their licenses for identification, and you have learned that you have to call South Dakota for a Mrs. J. Jones, the mother of one of the boys. The boy's wallet includes a telephone number for the mother. (When doing this script, have your back turned to the survivor as long as you are on the phone, so as not to have eye contact).

SURVIVOR 2 (Long-Distance Notification)

If the news is presented very soon after you answer the phone, make believe that you have fainted. If there has been sufficient time spent determining that you are the mother of this teenager (Mrs. J. Jones), making sure that you are sitting down, and leading up to the news gradually, react with horror and then begin either denying the possibility or bargaining by trying to find out if it was really your son or the friend he was traveling with.

DOCTOR 3 (Treating the family)

You receive a frantic call, which your secretary puts through to you immediately, from an adolescent you treat. (When doing this script, if you are on the phone, have your back turned to the survivor so as not to have eye contact).

SURVIVORS 3 (Stunned adolescent and then the husband who cries after his wife's suicide)

After just finding your mom dead in the bathroom, you call your family doctor and yell, "She's dead, mom has committed suicide!" Then ask the doctor, "Should I call Dad?" If the Doctor says he'll call dad, give the doctor a telephone number and then take the role of the father. When the doctor gives you, the father, the news, cry uncontrollably and ask repeatedly, "How am I going to live without her?" If the doctor says for you to call your Dad, get angry at the doctor, blaming him/her and accusing him/her of not caring.

DOCTOR 4 (Treating a patient with a mind of her own)

I've been treating a 33-year old woman with five children for her gall bladder problems. She requests birth control and refuses to consider any alternatives to the pill in spite of the fact that she anticipates surgery. She explains, "I get pregnant if he hangs up his pants! No way am I going to take a chance with a condom or a diaphragm." She did have her gall bladder surgery and went home. A few days later, you get a call from her. She is having trouble breathing. Is it a panic attack? Maybe it is a pulmonary embolism. The ambulance takes her to the emergency department where she expires. It is about 6 p.m., and you know her husband should be getting home from work shortly. (When doing this script, if you are on the phone, have your back turned to the survivor so as not to have eye contact).

SURVIVOR 4 (The husband who asks how to tell his children)

Keep asking the doctor, "How am I going to tell the children?; what am I going to say to them?"

DOCTOR 5 (The nurse says it was an accident)

A nurse from the hospital calls about a patient of yours who has been on a respirator. She says, "Someone took off Mr. Jackson's tube to clean it, and it looks like they didn't put it back in properly. He has suffocated. Looks like an accident, but we don't know for sure." The nurse continues, "You better call Mrs. Jackson and those five teenagers of hers. (When doing this script, have your back turned to the survivor as long as you are on the phone, so as not to have eye contact).

SURVIVOR 5 (Silent and then angry avoidance)

You are one of five teenagers who all end up with different understandings of the cause of their father's death. You are one of these survivors receiving the news. You are silent, then angry, vowing never to see the doctor again, and finally, you hang up the phone.

DOCTOR 6

You are a rural physician and called to the scene of a logging accident. You have been treating Bill, who drinks a lot, for over 10 years. For the last three days, there have been high winds, and he has been unable to fell any trees. The wind died down, and he got the "Chopper", a large tractor-like machine. His assistant had been reluctant to cut any trees because the wind could kick up at any moment. Bill's response was, "You can't get paid if you don't cut." By the time you have a chance to see Bill impaled on the instruments of the Chopper, his wife has arrived and runs out of her car toward the machine.

SURVIVOR 6 (Screaming and out of control)

You've heard that your husband has been hurt on a machine while logging, and you've driven out to the scene. You see the doctor and run toward him and the machine which is just behind the doctor.

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